

DÁIL ÉIREANN

AN COMHCHOISTE UM NITHE A BHAINNEANN LE MÍCHUMAS

JOINT COMMITTEE ON DISABILITY MATTERS

Déardaoin, 2 Nollaig 2021

Thursday, 2 December 2021

Tháinig an Comhchoiste le chéile ag 9.40 a.m.

The Joint Committee met at 9.40 a.m.

Comhaltaí a bhí i láthair / Members present:

Teachtaí Dála / Deputies	Seanadóirí / Senators
Holly Cairns,	Alice-Mary Higgins,
Seán Canney,	Eugene Murphy.
Jennifer Murnane O'Connor,	
Pauline Tully.	

* In éagmais / In the absence of Senator Fiona O'Loughlin.

Teachta / Deputy Michael Moynihan sa Chathaoir / in the Chair.

Aligning Disability Services with the UNCRPD and Considering Future Innovation and Service Provision: Discussion

Chairman: Apologies have been received from Deputy Wynne and Senators McGreehan and O'Loughlin. The purpose of today's meeting is to discuss the alignment of disability services to the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, the future systems and innovation of service provision. On behalf of the committee, I wish to extend a warm welcome to Ms Magdalen Rogers, executive director of the Neurological Alliance of Ireland; Dr. Niall Pender, principal clinical neuropsychologist and head of psychology at the neuroscience centre in Beaumont Hospital; Dr. Alison Harnett, chief executive of the National Federation of Voluntary Service Providers; Mr. Michael Hennessy, chair of the National Federation of Voluntary Service Providers; and Ms Natalya Jackson, board member of the National Federation of Voluntary Service Providers.

I must remind members that only members participating from the precincts from Leinster House can contribute to the meeting, which means those who are physically located on the Leinster House complex. In this regard, I ask members joining the meeting remotely to confirm they are on the grounds of the Leinster House campus prior to contributing to the meeting. For anyone watching this meeting online, witnesses are accessing this meeting remotely. Due to these unprecedented circumstances, I ask that everyone bear with us should any technical issues arise.

Before we commence formal proceedings, I must begin with some formalities and advise our witnesses on the matter of privilege. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given. They are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person, persons or entity by name or in such a way as to make him or her identifiable. I wish to advise witnesses giving evidence from a location outside of Leinster House to note that the constitutional protections afforded to witnesses attending to give evidence before the committee may not extend to them. No clear guidance can be given on whether, or the extent to which, the evidence given is covered by absolute privilege of a statutory nature. Persons giving evidence from another jurisdiction should be also mindful of their domestic statutory regime. If they are directed by the committee to cease giving evidence in relation to a particular matter, they should respect that direction.

Members are reminded of the long-standing parliamentary practice that they should not comment on, criticise, or make charges against a person outside the Houses or an official either by name or in such a way as to make him or her identifiable.

I call Ms Magdalen Rogers to make her opening remarks.

Ms Magdalen Rogers: I wish the Chair, committee members, and fellow presenters a good morning. On behalf of the Neurological Alliance of Ireland, I thank the members of the committee for the opportunity to appear in front of it today. Our umbrella organisation represents more than 30 not-for-profit organisations providing specialist supports to people with neurological conditions and their families.

I commend the committee on recognising the specific needs of people with neurodisability in extending an invitation to our group. According to the World Health Organisation, neurological conditions affecting the brain and spinal cord now represent the leading cause of acquired

disability worldwide, with an estimated one in three people worldwide affected by a neurological disorder at some point in their lifetime. More than 800,000 Irish people are living with a neurological condition, with an additional 50,000 diagnosed each year.

The UNCRPD has wide ranging relevance and implications for people living with a neurological disability. We want to focus today on one of the most critical articles of the convention when it comes to people in Ireland living with a neurodisability. Just to note, we identified many of the issues that will be raised today in our submission on lived experience to the committee back in November of last year. Article 26 of the convention calls on State parties to provide comprehensive rehabilitation services and programmes for people with a disability. The capacity review of disability services published by the Department of Health in July of this year specifically recognises the major shortfall in timely access to rehabilitation for people with a neurodisability and the critical need for investment in neurorehabilitation services.

My co-presenter today, Dr. Niall Pender, brings a front-line perspective on the importance of neurorehabilitation services from his role as principal clinical neuropsychologist in the national neuroscience centre, where he is confronted on a daily basis with the life-changing impact of conditions such as stroke, acquired brain injury and spinal injury as well as progressive neurological conditions, such as multiple sclerosis and Parkinson's disease.

The national neurorehabilitation strategy was published a decade ago in 2011 and the current programme for Government includes a commitment to its implementation. A three-year implementation plan was finally published in 2019 and it comes to an end this December.

I want to highlight to the committee today that Ireland will not meet its obligations under the UNCRPD unless and until the neurorehabilitation strategy is fully implemented. In our response to the draft State report in March this year, we outlined the serious lack of progress on the 2019 to 2021 implementation framework. First, the implementation framework committed to the establishment of community neurorehabilitation teams in each community healthcare organisation, CHO. Over the three years of the framework and in the decade since the neurorehabilitation strategy was published, only two additional teams have been funded, and only partially. Both of these teams are in the east, in CHOs 6 and 7, despite the lack of any proper neurorehabilitation service provision across the rest of the country.

Second, Ireland needs a minimum of 288 specialist rehabilitation beds for its population. Fewer than 30 additional beds have been introduced in the ten years since the neurorehabilitation strategy was published. The redevelopment of the National Rehabilitation Hospital, while warmly welcome and much needed, did not introduce any additional rehabilitation beds. The HSE steering group responsible for the implementation of the strategy from 2019 to 2021 met only twice in 2020 and has not met at all in 2021. We are seeking the oversight and support of the committee to address the serious delays in the implementation of the strategy to ensure that Ireland is in a position to meet its obligations to people with a neurodisability in this country under the UNCRPD.

The Covid-19 pandemic has given added urgency to the implementation of the neurorehabilitation strategy. The national clinical programme for rehabilitation medicine has highlighted that a significant proportion of patients admitted to ICU with Covid-19 are anticipated to have significant complex impairments requiring specialist rehabilitation consultant and multidisciplinary team input and may require transfer to specialist rehabilitation units, while many with milder symptoms will need access to rehabilitation in the community.

We are requesting that the committee write to the Minister for Health, Deputy Donnelly, urging him to implement the neurorehabilitation strategy and consider a joint motion calling for full implementation of the strategy within the lifetime of this Government, as committed to within the current programme for Government.

I thank the committee and invite any questions.

Chairman: I thank Ms Rogers for her opening remarks. I call Mr. Hennessy to make his opening remarks.

Mr. Michael Hennessy: I thank the committee for this opportunity to meet. The National Federation of Voluntary Service Providers: Supporting People with Intellectual Disability is a national umbrella body of not-for-profit organisations providing direct supports and services to people with intellectual disability. Across 57 organisations, our members support approximately 26,000 children and adults with intellectual disabilities and their families, providing

services and supports throughout the lifespan.

Our member organisations have community presence and connections across cities, towns and villages throughout the country. As two thirds of disability services are provided on behalf of the State by

the voluntary sector, we welcome the joint committee's invitation to us, as not-for-profit service providers, in the context of this debate. We welcome the focus of the Joint Committee on Disability Matters on the key area of reimagining the future for disability services to provide a more rights-based approach. The opportunity to listen to the lived experience of people with a disability and their families that has taken place at recent meetings of the committee has been vitally important, and their testimonies have been powerful and compelling. A key pillar of our work in 2021 has been to examine the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD, in great detail. We have brought together online our members from around the country to look at the status of the implementation of the UNCRPD, working through the Articles one by one, reflecting on the State report and thinking about how to implement a more rights-focused approach to service provision. Our board will continue this focus in 2022.

Following these workshops with our members, we have made a number of key submissions that reflect our views on the UNCRPD. These include our response to the draft initial State report, our participation in the development of the new housing strategy and our recent submission to the disability action plan 2022 - 2025.

As time is short for this opening statement, there are a couple of interlinked themes we wish to highlight. These include the need for sustained investment with multi-annual planning to address waiting lists in children's and adult's services, the requirement for new models of service delivery and improved cross-departmental working with a whole-of-government approach to the UNCRPD.

The disability capacity review has set out a very significant level of unmet need for disability services. These figures confirm the deficits described in successive pre-budget submissions by a range of organisations, ourselves included. Behind the substantial figures in the capacity review are individuals and families who are struggling to access the kinds of supports envisaged in the UNCRPD. It will take a number of years of sustained investment to address this level of unmet need. We are acutely aware of the unmet need in children's services and how this

impacts on children and families. We believe that the urgent completion of the reconfiguration of children's services and a sustained multi-annual programme of investment are required to address this unmet need.

The provision of a lifelong diagnosis of disability provides for the potential to plan early and provide the resourcing to support people well. However, current budget and planning cycles are annual in nature. These result in crisis-driven and emergency responses that do not result in the best outcomes for individuals, cause enormous uncertainty for families and are not best value for State funding. A multi-annual planning and investment framework is required to improve this.

Supports should be planned and implemented at the levels required by individuals to support their independence in line with Article 19. This requires a range of service delivery models that respect the individual's independence. These include personal assistance, home support, supported independent living and, for some with higher support needs, full-time residential care. These supports need to be put in place earlier, rather than in a crisis when a family carer becomes ill or passes away.

Article 19 of the UNCRPD focuses on the right to live independently with appropriate supports and in order for this to be achieved it will be necessary to provide the integration of housing together with supports. This will require substantial collaboration across the Department of Housing, Local Government and Heritage, the Department of Health, the Department of Children, Equality, Disability, Integration and Youth and other relevant Departments, including the Department Social Protection and the Department of Transport. There is an opportunity to put this in place through the new housing strategy and we are engaged with the process of consultation that is involved in developing that strategy.

Articles 29 and 30 address the right of a person with a disability to participate in public and cultural life. Supporting these rights is a whole-of-government challenge. The UNCRPD needs to be addressed across a range of Government Departments. Where there is a lack of clarity in terms of responsibility of Departments, it is the person - the citizen - who often falls between the stools and is left without support. We have highlighted in our submissions a range of areas including supported employment, housing and supports and transition planning for young people, where there is a need for improved collaborative working and a clear delineation of departmental responsibility.

At the individual organisation level, members of the federation have been working to transform services and supports with a number of initiatives. These include the development of individualised supports in day services under the new directions programme; collaborative work with local authorities to deliver housing and supports; supporting people to move from congregated settings to the community – there has been considerable progress but the work continues; and the establishment of successful programmes that demonstrate the value of transition planning and tailored employment supports.

At the national level, the federation has had a focus for many years on developing initiatives that support innovation. We are happy to share details of these with the committee. Some of them include our next steps community of practice and the immersion programme; the Informing Families evidence-based best practice guidance; the person-led research of the Inclusive Research Network; and our recent work with the older persons working group. The learning from these organisational and national initiatives can provide impetus for further development of strongly individualised, person-centred and person driven approaches.

The collaborative approach undertaken by services together with the HSE during the Covid-19 pandemic provides fertile ground for continued partnership in developing services into the future. We attach considerable importance to the work being undertaken to address challenges highlighted in the Catherine Day report and through the work of the health dialogue forum chaired by Mr. Peter Cassells. Our services are ready to work with the key stakeholders to develop and reimagine services and supports for the future, to ensure the people we support can access their rights under the UNCRPD and live life to their full potential as valued members of their communities.

I thank the committee for the opportunity to meet with it on this topic. We are happy to take questions from members.

Deputy Pauline Tully: I welcome the witnesses and thank them for presenting here today at our committee. I wish to put questions to Ms Rogers of the Neurological Alliance of Ireland first. Ms Rogers stated that the neurorehabilitation strategy has not been implemented and, in fact, only two of the teams have been partially established in the past three years. She also mentioned that 288 specialist beds are required. How many beds are available at the moment? According to Ms Rogers's written statement, 50 beds have been added; however, in her opening remarks, she said 30 additional beds. Is it 30 or 50 additional beds and how many beds are available in total? Why has this strategy not been implemented? Can Ms Rogers say whether it is a lack of funding or a lack of suitably qualified personnel to staff the teams?

Ms Magdalen Rogers: I thank Deputy Tully for her question. I will answer first on the existing number of beds. It is difficult to get a handle on the number of existing beds, to be honest, because the steering group on the implementation of the strategy has met so infrequently in terms of mapping what is in place. There are 120 beds in the National Rehabilitation Hospital. The redevelopment of the National Rehabilitation Hospital into effectively a new hospital - while very welcome and a fantastic facility - did not introduce any additional beds. There are beds in a Roscommon unit and beds recently brought on stream this year in Peamount Healthcare. Again, these are very welcome developments. To answer the Deputy's question directly, we find it difficult to get a handle on exactly how many of those 288 beds are in the system. The last estimate from the rehabilitation medicine programme stated that we have fewer than half of the specialist rehabilitation beds we need.

To answer the Deputy's question as to why the strategy has not been implemented, we see it as a matter of funding. Repeated submissions are made to the Estimates process each year for the funding of the strategy and of the rehabilitation teams. Unfortunately, that funding has not been forthcoming. In relation to the teams in community healthcare organisations, CHOs, 6 and 7 that demonstrate our project on the implementation framework, that is outlined in the disability capacity review this year as costing €5.2 million. There was only €2.6 million provided for the establishment of a managed clinical network in community healthcare organisations 6 and 7. That is only half of what is required to put in place that service. As I said in our submission, that is the one development in the neurorehabilitation strategy, the addition of some inpatient beds in Peamount hospital and the development of two implementation teams in CHOs 6 and 7, none of which is on the ground yet.

Deputy Pauline Tully: This is something this committee definitely needs to support and to push for its implementation, something we all would be happy to do. I will move on to the National Federation of Voluntary Service Providers. How do you envisage service provision changing to align with the UNCRPD? To move towards ratification and full implementation of the UNCRPD we must promote and support independent living. There is probably a need for

personalised budgets so that people have a choice on how to live all aspects of their lives. We had witnesses before us who talked about service provision and the difficulty they had in identifying a suitable placement, for example, for a school-leaver because many of the facilities were located in industrial estates and did not look like educational facilities. Indeed, some services are quite poor in that regard. I heard of a person who has Down syndrome and completed the leaving certificate but in the service was put to colour in pictures. That caused regression rather than progression. Many will say the service provided is of a one size fits all type, with a take it or leave it attitude. We know one size does not fit all. It has to accommodate all levels of need. I note the witnesses state that their members have been in consultation on the new housing strategy. Can they clarify please, is that the service users? If we are properly to implement the UNCRPD, people with disabilities and DPOs need to be involved in the consultation, in line with the “nothing about us without us” concept. To whom are the witnesses referring?

The witness also mentioned a collaborative approach undertaken by services together with the HSE during Covid-19. Many people felt totally abandoned by service providers and the HSE during Covid-19, especially in the first six months. Many people have said they had no support whatsoever and indeed they queried where the budget for their service user had gone in that time because they certainly did not receive any of it and they had additional costs during that time.

Dr. Alison Harnett: On the question of imagining what services should look like in the future, in our opening statement we acknowledged the important lived experience that has been expressed. We agree with Deputy Tully on the idea of “nothing about us without us” and the primacy of the lived experience and that voice. From the service provider’s perspective, which is the umbrella body we represent, there is a need for multiannual funding to enable planning. I will address the first question on residential matters and then move on to the day supports. The only options that have been funded in the past number of years have been the emergency crisis places. Typically services are delivered too late in a traumatic situation when a primary carer, who is often an elderly parent, has passed away or has become ill. If we imagine a series of steps on a ladder, people are receiving full-time residential support at the most traumatic time of the journey that it could happen. If we could begin investing in multiannual planning, as witnesses in previous debates have talked about, the predictability of the service user’s diagnosis allowing that planning, then we could have continual investment in more rights-based approaches such as personal assistants, personal budgets, the home support and moving up those steps of the ladder as appropriate, as required, and in line with the preference of the person. That investment has not been available in the past number of years. All that has been available was purely crisis and emergency response. That is not delivered in a way that allows the person transition into it and develop his or her independent skills as a young adult or as an adult in his or her 20s or 30s who expresses the view that he or she wishes to live outside the family home of origin. We are calling for the multiannual approach to planning, budgeting and delivery of service provision that responds to the UNCRPD and the ADM, and allows people to express and develop their independence in how they live.

In terms of the one size fits all day services, our ambition is to move far beyond that and to have a multilayered approach. There have been many good initiatives that need to be further developed. There has been, for example, a wonderful series of transition planning developments where young people are approached two years before they leave school. If we look at the WALK PEER programme, the Cumiskey Ross ability programme, the outcomes from supporting young people at that early stage have been fantastic. That is what needs to be developed and improved. It needs a cross-departmental approach to planning. We call for the inclusion

of career guidance for young people in special schools because without that we have very low ambitions which suggests that the only option would be a full-time day service placement when actually, what we should be looking at are employment and education opportunities for young people who attend special schools. We do not have career guidance counselling in those locations at the moment. There is a listening and an acknowledgement of the lived experience that has been expressed here. There is openness on the part of service providers to develop in all the ways described. There are initiatives under the New Directions programme and others that include such things as the transition planning.

In regard to the other two questions, on the consultation on the housing strategy, we would like to compliment the running of the consultation process for the new housing strategy. It has been the most inclusive process I have been involved in during my time with the National Federation of Voluntary Service Providers. It has involved surveys of people with lived experience on both the steering committee developing the programme and in the consultation rounds, which have taken place with DPOs. As a service provider umbrella body, we were involved in that steering committee alongside those organisations that represent people directly. There is very much a holistic, collaborative approach to the development of the strategy. It is probably a model that we would like to see replicated in future strategies. It is inclusive of people with lived experience, service providers and the key stakeholders.

In terms of the collaborative approach with the HSE during Covid-19, an immediate response was required to support people who lived in residential services, many of whom did not normally reside in their residential place until day services closed for public health reasons, and needed to be supported 24 hours a day in the residential space because they were not attending their day services. This required the application of resources from the day service sector into residential supports to allow that support be provided. When we examine the mortality and infection rates for persons with a disability who had significant risk factors at the beginning of the outbreak of Covid-19, in comparison with other jurisdictions, the outcomes have been relatively far fewer. There has been a very low level of infection and a low level of mortality. That has come with an enormous price for families who experienced reduced support in the day service locations during the Covid-19 pandemic. We fully acknowledge the experiences Deputy Tully described. We were in compassionate response to those families but the resources required to ensure a safe service was provided in residential services had an impact on families and we acknowledge that.

Chairman: I thank the witness. I now call Deputy Jennifer Murnane O'Connor.

Deputy Jennifer Murnane O'Connor: I thank all the witnesses. I will address this to Ms Rogers. I fully support the implementation of the strategy. On the steering strategy, it seems that from 2019 to 2021 the group has met only twice and there has been no meeting this year. That is a concern. I ask that as a committee we write to the Minister for Children, Equality, Disability, Integration and Youth, Deputy Roderic O'Gorman, requesting that this neurorehabilitation strategy and the steering group get back up and running. Time is of the essence. I ask that from today we fully support that. Given that there are more than 26,000 members, both children and adults, are we really aware of the different strands of disability? Have we actually got the correct data on this? We have many different types of disability and everybody is trying to work together, but are there proper data? How can we ensure disability awareness raising on the level that is needed by the UNCRPD across all sectors? We need to develop a disability awareness raising strategy in line with the human rights and social model of disability and include a roll-out of all disability awareness raising for all staff of government

and the departments of public bodies. That is important because it is all about awareness and training. I know people who are wheelchair users and they cannot even access some buildings. Everybody needs training, including ourselves, so that we are more aware. A lady contacted me three weeks ago whose daughter was in a horrific car accident with the mother, which left her in a wheelchair for life. That mother cannot take her daughter on some footpaths, or bring her into some buildings. Obtaining information is another issue. These are the issues we need to address. Another person with a bad disability contacted me. He is in hospital and we cannot get him home because there are no homecare packages for him. Funding is a huge issue. We cannot allow this to happen to the most vulnerable people in our society, people with disabilities. We must ensure there is funding. We have a duty of care to children and adults with disabilities. Is there a lack of communication within different Departments? The witness spoke about housing and it is great to see they are working with the Department of Housing, Local Government and Heritage. As councillors and Deputies we constantly fight for ramps, adaptation grants, bedrooms and heating. People with some disabilities feel the cold and need extra heating. We need to build more houses that are adapted to cater for specific disabilities. We must give people the choice between going into care, staying at home, going to daycare services or maybe into a service where they can have both. We have many criteria to meet, and part of this has to be in the strategy going forward. We need to make sure the Minister for Housing, Local Government and Heritage steps in here to do that. Hopefully Ms Rogers and Mr. Hennessy can answer those questions.

Mr. Michael Hennessy: I might defer to one of my colleagues on the housing strategy.

Dr. Alison Harnett: I will speak about that. There is a campaign currently underway to look for revision of Part M of the building regulations. Currently Part M requires a certain proportion of wheelchair visitable accessibility, but without the accessibility becoming wheelchair liveable we will not be able to house people who have a need for wheelchair liveable housing. It is important that universal design becomes part of the design features of many of the houses in the future. As people's accessibility needs change, they can be met. We are calling, along with all the other umbrella bodies and advocacy groups, for a review of Part M of the building regulations so that there is a minimum amount of the supply pipeline with wheelchair liveable rather than wheelchair visitable housing. Those targets need to be part of the regulations. Our experience is that there has not been wheelchair livable accommodation delivered to date. The revision of Part M is potentially the area of concern, and the delivery of a pipeline of supply, because currently the supply is not meeting the demand for accessible housing.

Dr. Niall Pender: I am happy to address some of those questions. I thank the Deputy for giving us the opportunity to talk about these issues today. Neurological disability is in a very chaotic, unclear and unstructured position at the moment. We do not have data on the number of people with any of these conditions. We have some minimal epidemiological data to give us the number of new cases that might be diagnosed but most of our data come from international studies extrapolated to Ireland. We do not have a very clear picture of the number of people currently living with neurological disabilities and the impact of those disabilities on their conditions. One of the challenges we have is that, because there is no clear strategy for what happens once a person is discharged from hospital, people fragment. Many people disappear into the community and struggle on their own. This is why many people describe themselves as being hidden. They disappear into the community and try to manage their disability with the help of their families. These are people who were living full lives and suddenly had everything change with a diagnosis, an injury or an illness.

In other cases family members have to use Google to find out the symptoms and where they can get treatment. For any other illness a person would not have to find out what were their symptoms and what treatments were available. If a person had a cancer diagnosis he or she would not need to find a radiation oncologist or find a chemotherapy service. Many of our patients with brain injury have to do this. They have to find a neurophysio, a neuropsychologist or neurologist. In the case of epilepsy, mobility difficulties or balance problems, they have to find treatments themselves. There is no coherent, consistent programme where somebody slots in and follows the person through discharge into the community, transitional living units - we have one or two possibly in the community - community neurorehabilitation and into long-term care. The system is haphazard.

It is also haphazard based on where the person lives. There are some spots in the east, in Dublin, and in Limerick and possibly in the south-west and Cork. If a person with a disability lives along a line from the south-east up to the north-west there are very few services for them. Access to services depends on where the person lives. A person might be discharged to a community team and have some resources, or he or she might not, in which case it is up to the person and his or her family to find the services. Not only are family members trying to cope with the impact of the illness and disability but they are also trying to find services and treatments. Some people return to work after a couple of weeks after a major brain injury and everything falls apart and they lose their jobs. Some people never get back to work or education again. We know the rehabilitation systems work. They can help people and give them a structure. The information and interventions these people get make a difference if they get them in a timely way. We know from many international studies that even up to 40 years post-injury a person can still benefit from rehabilitation, if he or she gets it. Some of the international data would suggest that 40% of people who are rough-sleepers have had a brain injury at some point and their lives have fallen apart for lack of services. Prison populations have high rates of people with brain injuries. We know there is a cost to this in regard to people's capacity to live independently, to participate in society. We need to put in place the rehabilitation structures we know exist in many parts of the world.

Mr. Michael Hennessy: I want to address part of Deputy Murnane O'Connor's question on housing. In the development of the housing strategy we are advocating that there be proper provision for people with a disability. My colleagues addressed the issue of wheelchair accessibility and wheelchair liveable housing. However, not all support needs are visible. People with autism may not have any visible physical needs, however when it comes to housing they have particular needs. We advocate for the fact that, while we want the people we support to live in mainstream society, their houses should look no different from anybody else's. For a person with autism, the built environment is critical in the provision of supports. A person with autism experiences life differently from other people and we respect that. That often requires the development of bespoke day services or residential buildings to reflect the person's needs.

Deputy Jennifer Murnane O'Connor: Does Mr. Hennessy find that when families are applying to the local authority for housing, that autism is a criterion that is put to the top of the list? Whether a person has a medical issue, a disability or autism, does Mr. Hennessy find, from working through the different housing groups, that people are being prioritised?

Mr. Michael Hennessy: It is a developing situation. The number of people with an autism diagnosis who seek to access services, be they day services or residential services, particularly where autism is their primary need even though there may be other issues, is increasing. It is a challenge to develop services that meet that need. It is an area which needs further work and

something for which we advocate. Not all support needs are visible, but that does not mean they are not there.

Deputy Holly Cairns: I thank the witnesses for appearing before the committee today. Their experience and insight as service providers are essential to understanding how we improve disability supports, especially in the case where the majority of disability services are provided on behalf of the State by the voluntary sector. My first question is for the National Federation of Voluntary Service Providers. If I have time afterwards, I have more questions. I welcome the acknowledgement of the unmet needs of children's services and the urgent need for multiannual investment. I raised these issues last week with the HSE and with the Minister for Children, Equality, Disability, Integration and Youth, Deputy O'Gorman. The disability services programme is currently failing due to a lack of staff and resources. Using my constituency as an example, although I am sure it is the case in many constituencies, we have worryingly long waiting lists for assessments, not to mention incredibly poor access to therapies. After assessment it may be that a year and a half later a person has only received an hour or two of those essential therapies. The federation is at the front line of a situation where it is caught between inadequate Government funding and the needs of children and young people with whom it works. The federation referenced the Department's capacity review, which says it all. The Department in its own review said we need €350 million to meet the unmet needs of people with disabilities, and then there was an additional €65 million allocated. Of course, it has not come close. Will the witness outline what needs to be done to address the issues in that area?

Mr. Michael Hennessy: I will address that. In regard to the children's services, there are two things we would say. First, the progressing disability services, PDS, model is being implemented throughout the country. In part of the country it was implemented several years ago, in other parts the transition is taking place just this year. It represents a huge upheaval of services. Teams are being merged, people are moving from one team to another, and during or immediately after that transition teams are probably not at maximum productivity. We advocate that completing the transition as quickly as possible and getting those teams functioning and firing on all cylinders is important. We notice that parts of the country that reconfigured as far back as 2013 are running better than parts that are in the midst of the reconfiguration. Getting that reconfiguration completed and running as quickly as possible is important.

The other aspect, which is unavoidable, is resourcing. There were waiting lists before the new children's model PDS came into place, and they remain afterwards. There are more than 90 child development network teams, CDNTs, throughout the country. There is significant disparity of resourcing among teams. There are teams with good ratios of staff to children being supported, but there are other networks where resourcing is a long way short. We advocate for multiannual programme funding particularly to bring the resourcing of the CDNTs up to levels adequate to meet the needs to get timely issuing of initial assessments, family support plans, and timely interventions.

Ms Natalya Jackson: Speaking on the progressing disability services, many networks reconfigured only in October, moving from the unidisciplinary to the multidisciplinary model and that family centred practice. There has been good progress on working with the HSE and other lead agencies, and I acknowledge that. It is about equity of access for children also. What that has resulted in though, from the mapping exercise, there are some networks that have increased from maybe 900 children up to what they thought might be 1,300 children and now might be 1,800 children. That exercise is ongoing to see what resources are needed. Significant funding was received and recently another 100 therapists were recruited and governmental funding

came down for that. Much of that is at basic therapy level. One of the things we need to look at going forward is the conversion from basic to therapy grades. Because many networks re-configured at the same time, there are large recruitment gaps. When going out to the market, networks are looking for the same individuals. It was useful to see that collaboration approach in one of the Government's action plans with third level education because in the coming years we will need further training courses for therapists. Between now and 2032 there is €54 million identified for children's services. Much of that is with front-line services. Much work has been done but we are looking at that intervention so that we can get people off the waiting lists. Early intervention involves building up the skills of therapists and specialists across the areas.

Deputy Holly Cairns: I appreciate the responses and I understand the reconfiguration is important. As Mr. Hennessy said, sometimes allocation of staff for that reconfiguration falls short. In one very populous area there is 0.5 of a nurse or 0.5 of a physiotherapist allocated. The concern is that even when those reconfigurations happen, without the funding the Department decided was required, the people will be still on those waiting lists. When they finally are assessed they sometimes do not get the services they need. As a committee we will keep pushing for adequate funding to be allocated. We understand the pressure that puts on those network teams that try to provide a service and lack the resources. Another thing that was noted was poor supports that respect and enable individual's independence such as personal assistants and supported independent living, and somebody referenced the geographical lottery with respect to this. Whether a person can access independent supported living depends on the part of the country in which a person lives. This is a tricky question that was highlighted both in recent weeks and throughout the past year by several witnesses who came before the committee. Will the witness elaborate on how we can put in place a system that can guarantee independence in line with article 19 of the UNCPRD. That is a question for the National Federation of Voluntary Service Providers.

The Neurological Alliance of Ireland highlighted the current shortage of services for neurological conditions and the increasing numbers of people affected by those conditions. Will the witness elaborate for the committee the impact on individuals of the lack of rehabilitation and support, especially in terms of employment and education?

Dr. Alison Harnett: I thank Deputy Cairns for her question. As an umbrella group of service providers, the national federation has been looking at this question of independent supported living for quite a number of years. It developed a community practice which was a shared earning space for more than 26 organisations collaborating to look at how to develop individualised supports into the future and where it was possible to do so. There have been many different areas of support and little initiatives such as the Genio grants, and there has been the service reform fund. These initiatives have allowed us to put in place options for a range of people and to share learning, with the person with the lived experience sharing his or her experience of what it is like to change. People have described what it was like to live in congregated settings and then move to independent living and having their lives transformed. We learn the most from the people who shared their experiences, as well as their families, the people who support them at the front line and all the way to the management. It is a question of how you develop that. We have learned that the outcomes from the Next Steps shared learning are that it is possible to provide independent supported living for people of all ranges of needs, and support requirements. What is required, and it is probably going to be the theme of today, is the multiannual investment programme. If we continue to respond only to the crisis and emergency situations, that is typically going to be very expensive, without the kinds of outcomes we are talking about, where people get to choose the kind of support and life they need. The choice to

live alone or to live with other people, in student accommodation as a third level student or to live near one's employment is not possible when responding in a crisis. We have proven that in Ireland it is possible to provide the supports for people to have wonderful outcomes in their lives, to experience independence in a way they have not up to now. That is the case with people with all ranges of ability and needs. We know it can work, and with the correct investment it will work. It is about developing at the different stages and levels that people need. Some people have complex medical requirements that will require nursing support. Other people require a couple of hours support, with somebody to look in and ensure they get a little help with cooking or buying groceries. We should not provide the top level of support unless that is required because it impacts on people's independence. To be able to do that, we need multi-annual funding to allow us develop those options at the right time in a person's life, to respond to the person's will and preference.

On the other side of the coin, as adults without disabilities, people have the choice to move out of their family home of origin at a particular time in life when it is right for them and their families have the opportunity to plan for a future. Many family carers are living into their 70s and 80s and have not had the opportunity to plan nor the visibility into the future for their loved one. That is not right for the person who is supported and may wish to live independently and it is not good for the health and well-being of the elderly carers. The acknowledgement in the disability capacity review of those cohorts of people has been very welcome. What we need to do now - apologies for giving the same answer to many of the questions - is to get the multi-annual investment programme to allow us to implement those things.

Chairman: I call the witnesses from the Neurological Alliance of Ireland.

Ms Magdalen Rogers: I will let Dr. Pender reply to Deputy Cairns's question on the impact because that is something he sees every day. On the point about the vocational and educational supports for neurodisability, I want to stress that the neurorehabilitation strategy is not just about beds or medical teams. It is about the full range and gamut of supports that people living with a neurodisability in Ireland need. It is not just about hospital beds, but the full range of supports to live well with these conditions. We talked about progressing children's disability services this morning, but I emphasise that for adults living with neurodisability in Ireland, the neurorehabilitation strategy is as critical as the progressing disability services to children. The fact that it is not progressing is leaving these people behind. I now ask Dr. Pender to describe the impact and how these people are being left behind because of the lack of implementation.

Dr. Niall Pender: The impact is devastating, depending on whether it is an acute injury, maybe a head injury or a diagnosis such as a brain tumour, stroke or a neurodegenerative diagnosis such as Parkinsons, MS or motor neuron disease. The impact goes across a range of functions because the complexity of the brain is so difficult and so high. A person can have significant physical disabilities which limit his or her capacity to interact with the world physically, and that may be paralysis, substantial hemiparesis, limb difficulties, visual or auditory sensory problems, headaches, balance difficulties, but also the hidden pieces which are more challenging. This is the piece we see from the relatives when people come back, such as the psychological, cognitive or behavioural piece. People present with difficulties around memory, language, controlling the world, planning, problem solving, sometimes volatile emotion or depression and anxiety. About 40% to 50% of relationships do not survive a severe brain injury. They break down because there are no supports. The person is different, the role has changed. Many patients with severe brain injury do not get back to work. Younger people do not get back to college and they are stuck at home. They need substantial support. Organisations such as

Headway, Acquired Brain Injury Ireland and Quest Brain Injury Services in Galway are voluntary bodies which do a great deal of work to try to get people back, but it is a drop in the ocean. The people they see should have gone through a year or two of complex neurodisability before they even get to these organisations; this should be only at the last stage. At the moment the voluntary bodies are scrabbling around for funding to provide these services for people living in the community who are trying to get back into the world again. It could be anything, such as trying to get to the shops to get food, which is an enormous task for somebody after a brain injury, who may be forgetful, have a memory deficit or may be irritable. During the early stages of Covid-19 we saw how patients could not learn the new things so they were getting into difficult situations about masks and social distancing because they just did not understand the new rules. That caused all kinds of conflict.

There was a question earlier about information. Most people do not understand a brain injury, because in many cases the people look the same. This is similar to the autism issue where people look normal yet struggle with an enormous degree of difficulty on a daily basis. Add in the care-giver piece where a relative, sometimes a child, is trying to care for the relative, trying to get his or her life back and get him or her back into the community again. It is such a struggle. I see people coming back into the clinic maybe a year after being discharged. An acquired brain injury such as a car accident or coming off a bicycle - I see two or three bicycle injuries every week involving concussion - can knock people out for a year after the accident because they do not have services and cannot get back to work or college; they struggle and their moods deteriorate. We see it after sports concussions. They are at the tip of the icebergs in terms of the mildness. At the extreme end of severe brain injury where people need residential care, we have young people maybe in their 20s in nursing homes for the elderly and they are sitting in the corner of a room without resources of any kind. The impact on a daily basis on somebody with a neurodisability is enormous and it takes its toll on the family. There is a famous quote that a brain injury is a family affair. It takes its tolls across the family. Relationships unfortunately often break down. Young children are really affected by an adult with a brain injury in the family. Their lives change overnight and there are no resources to facilitate that. They should get family therapy and counselling as well. That is the importance of the neurorehabilitation strategy. It outlines the continuum of care that people should get from the point of their initial diagnosis and early treatment when everybody is optimistic. They go from a point that, with a devastating diagnosis of a brain injury, they survive, they get out of the acute hospital and everything is great and positive, and suddenly they are lost. They have no idea where to go or to whom to turn. That is why the neurodisability strategy and neurorehabilitation strategy are so important, because they provide that framework and scaffolding that allows them to benefit from neurorehabilitation.

Chairman: If members could bear with me. Senator Higgins has to step out between 11 a.m. and 11.20 a.m. so if it is agreeable to members I will call Senator Higgins before Deputies Seán Canney and Eugene Murphy.

Senator Alice-Mary Higgins: I thank the Chair and my colleagues. Dr. Pender has answered one of my questions about what happens after the hospital and after the rehabilitation period. That is something on which I have had feedback. It is as if you get to a certain point and almost your whole job is rehabilitation and everything is focused on that. Then you are back into day-to-day life, with all of its very different tasks that are different from what you were just focusing on. Some of these tasks are seasonal and you encounter different challenges at different times of the year. There are challenges in relation to what goes on for your family and how you can support, or struggle to support, them. Dr. Pender made the case very well about the

importance of the community supports piece and that follow-up support. That is really important. Will Dr. Pender comment on what community based rehabilitation services exist and how they can be resourced? Are they uneven?

The witness from the federation mentioned engagement and I have a question arising from that conversation. What does the national federation's engagement on the housing strategy look like? Is that central? For example, every local authority area, as I understand it, is doing a housing needs assessment at the moment. That is a ground up piece of how the housing needs of persons with disabilities are being addressed. Is it being recognised in the housing needs at that level, and not just in hard numbers, that there will be a large cohort of people with disabilities, many of whom will be in households?

On the more top down piece, this committee has raised concerns about the inadequacy of things like Part M of the building regulations. Certainly, others in the committee and I have raised issues in regard to the national development plan and the importance, not just in health facilities, but in all of our buildings, that we have conversations around disability. Is the federation using its engagement to push forward universal design as a general standard?

There are a couple of projects that the federation had prior to the UNCRPD, including the next steps programme, the informing families programme and a number of programmes within that. Have the programmes all been reviewed now in terms of the new empowerment frame of the UNCRPD, that is, the rights-based approach? How has the federation examined its own programmes? This committee has been looking at reframing things; it is not just about getting services to people but it is about the empowerment frame as well. The three programmes I am interested in are the next steps, the informing families and the older persons working group. I used to work with Older & Bolder and there is much overlap there. Is there a common engagement or common cause that has been found in terms of pushing the agenda? Universal design is one example.

Retrofitting and adaptation tend to be separate tracks at the moment and I have been pushing for them. However, for example, people with disabilities and older people often spend more time at home and are more vulnerable in terms of fuel poverty. Should there be an all-in-one grant for people that combines retrofitting and adaptation?

Mr. Hennessy mentioned multi-annual funding and we all heard him; it is clearly important. Within multi-annual funding, is it important to build in flexibility to allow for response? Instead of getting three years to do the same thing, would it be better to have a guarantee of three-year funding that comes with flexibility so that those who are using the service can give feedback about what does and does not work or what needs adaptation, so that feedback can be met with flexibility, responsiveness and empowerment? What is the importance of non-directed funding, that is, funding that allows for a response to a demand or request?

There were comments made on the personal needs assistant. The statutory requirement to home care that was due in the programme for Government is now being supplanted and there is beginning to be something of a statutory entitlement - or should be a statutory entitlement - to personal needs assistants. Both are, of course, important. What progress has been made in terms of that statutory entitlement to home care or to, also importantly, personal needs assistants? Until there is a statutory entitlement, people will still have a dependence on a patchwork on public and private provision.

Chairman: Who would like to lead off on Senator Higgins's points? I call Dr. Harnett.

Dr. Alison Harnett: I am happy to come in on some of those and points my colleagues might wish to comment on some of them also. On the housing question and what our engagement looks like, as I mentioned earlier, it has been a model of good engagement. A survey has been carried out as part of the consultation for the strategy and more than 1,400 people responded, from people with lived experiences to other organisations like ourselves. There have been detailed submissions and we would have made a complex and detailed submission specifically based on the UNCRPD and how that interlinks with the new strategy. There have been focus groups with disabled persons organisations and with the national federation, specifically as a service provider body for a large number of people who have an intellectual disability and with other umbrella bodies. The Senator mentioned the housing and disability steering groups at local authority levels. As the Senator said, they have been developing strategic plans, and we expect the strategy to speak to each of those levels. It will speak to the national level and it will speak to how the housing and disability steering groups are strengthened in the future and how their work will continue at local authority level. The Senator was probably just looking for some detail on our engagement to date.

Senator Alice-Mary Higgins: If copies of some of those submissions are available, that would be very useful.

Dr. Alison Harnett: I am very happy to share our submission as the national federation. The housing agency is co-ordinating the strategy consultation so it may be in a position to provide others, but we can certainly provide our housing submission if that is useful to the committee.

In terms of Part M of the building regulations and the need for the pipeline, in both our response to the draft State initial report and the UNCRPD and in our housing submission we have been advocating for welcoming communities. It is not only about having housing that is specifically for people with disabilities; it is about having universally designed housing that is adaptable as people's needs change. It is about having housing that is usable for young parents with buggies, for an elderly person who might have walking and mobility requirements and that is adaptable for people with disabilities. As Mr. Hennessy outlined earlier, there can be many different reasons a person might need an accessible approach. This can include additional space, for instance, to ensure that somebody can stay overnight with the person who needs support, or it can be for the storage of equipment. Therefore, flexibility in responsiveness in the allocation of social housing is required so that it can be understood that there may be additional space needed in response to particular needs and that a universal design may be required. That is something we would strongly support.

As we have earlier outlined, there are specific requirements that need to be upgraded in relation to the wheelchair liveable rather than wheelchair visitable. Welcoming communities would be the track that we have taken. It is for everybody and it needs to be welcoming. It would benefit everybody if we have welcoming communities and housing supply. This should be included in the built environment in our communities and not just in our homes, because there is no point in having accessible homes that one cannot get to. That means looking at transport and the paving outside the home as well what happens inside the home.

In terms of our projects and whether we have reviewed them in light of the UNCRPD, we were as thrilled as everybody else in 2018 when the State ratified the UNCRPD. However, of course the UNCRPD had been available to us before the State ratified it. Rather than reviewing, and we need to constantly review our work, we set up those projects in line with the UNCRPD. The Informing Families project is a set of evidence based best practice guidance that was developed in collaboration with families, service providers and healthcare professionals

throughout hospital community and disability services to look at the way in which we provide the diagnosis to families. We were told by families that many of them were not being given a hopeful outlook when being given the news of their child's disability. This is what we are talking about when we speak about the options that are there later in life and the ambition that we have for young people in their schools, employment and education. We need to help professionals to see disability as only one factor in a person's identity. We need to support families to celebrate the birth of a new person who has a disability as one aspect of his or her identity and that he or she is a brother, daughter, son, a welcome member of the family who will have additional challenges and support needs. Informing Families is hoping to develop that understanding from the very first moment a child is born, that we all need to have welcoming communities, as a society. Within Next Steps it is utterly possible for people to be supported at the best level of their potential. It is about beginning that from the first transition, which is the moment a family is informed a child has a disability. We developed those post the 2006 development of the UNCRPD so we were very much enabled and facilitated in our work through the thinking in regard to the UNCRPD. We certainly did that in Next Steps as well. We thought about what the UNCRPD asks us to do. It is around developing people's independence and supporting them in the choices they would like to make.

The older person's working group is a very exciting piece of work because it collaborates with the Trinity Centre for Ageing and Intellectual Disability, which through The Irish Longitudinal Study on Ageing, the IDS-TILDA project, identified key health inequalities that exist for people with intellectual disabilities, specifically older people. Through that, as service providers we listen to that research and to what are those health inequalities. It is important to link that back in with mainstream policies. Looking at the Healthy Ireland framework, a very healthy development in the past two years has been the development of the national memory clinic for people with intellectual disabilities. People who have a potential diagnosis of dementia have access to this pathway to have their diagnosis assessed. That had been unavailable in many communities. Some parts of the country had access to memory clinic services and others did not. The National Federation is part of the steering committee of the national memory clinic. There are many opportunities for us and we need to continue to develop all the time. We must continue reviewing and challenging ourselves in our practice. Through those initiatives we look specifically at what the UNCRPD asks us to do as service providers. Those initiatives aim to do that.

In regard to retrofitting, adaptation, cost, and fuel poverty, as a group of six umbrella bodies we strongly call for the Cost of Disability Research report to be published so that those additional challenges that might exist for people with disabilities in their homes, with heating and many other areas of their lives, could be responded to through a cost of disability payment. I agree with Senator Higgins that there needs to be a co-ordinated approach to retrofitting and any other initiatives.

I will defer to my colleague on the question around flexibility and how we support our budgets.

Mr. Michael Hennessy: On the the question of flexibility within multiannual funding, we would certainly advocate that within that funding there would be ring-fenced funding for a series of progressive models to support people at differing levels. In terms of home support, supported living, semi-independent living and support packages, the Disability Capacity review identified that 64% of the funding went on full-time residential support. That will be still important in the future. It is important today, but we would like to think that in the future the

funding will be directed at a range of models rather than such a high proportion going to one model. In regard to the statutory entitlement schemes on homecare, I would like to raise the point that as they exist and are envisaged, those seem to refer to people over the age of 65. For a person with a disability, age-related needs typically kick in much earlier, possibly as early as the late 40s or early 50s, and that needs to be recognised in any such scheme.

Ms Magdalen Rogers: To come back to Senator Higgins's point about the gaps in community services, and where they exist, we in Neurological Alliance of Ireland, along with the Disability Federation of Ireland, are embarking on a project in 2022 to map where community neurorehabilitation services exist and where they do not. While that is an important piece of work, there has to be a context for it. I stress to the committee that we are in limbo. People with neurodisabilities in Ireland are in limbo at the moment because of the lack of progress on implementing the neurorehabilitation strategy. Unless that is active and up and running, we do not have a space to which to bring the outcomes of that mapping in order to identify the gaps. I again stress that for people with neurodisabilities in Ireland, the implementation and progress on the neurorehabilitation strategy is key, as a pathway to identifying needs in so many different areas. Employment, education and housing will all stem from implementation of the neurorehabilitation strategy and that process being up and running.

Deputy Seán Canney: I apologise that when the meeting started I was in the Dáil speaking on the Health (Amendment) Bill and that is why I was late joining the meeting. I welcome the witnesses. I read their introductory presentations which are very coherent and set out some of the issues. I want to begin with neurology as it is close to my heart in Galway where we have a shortfall of nine neurology nurses. There is a campaign at the moment to try and get them in place. It is frustrating that the strategy has not been implemented, and year 3 of it is running out now. I would like the witnesses' insight into why it has not been implemented. Is it due to lack of political will? Is it lack of resources or drive from within the HSE or where? Where can we start pushing to ensure it happens? Listening to the webinar on Monday, there were two witnesses who presented their own personal stories. They were powerful. It is sad that it is necessary for people who have an acquired illness to bare their souls to try and get something going. We want the strategy implemented. My view of strategies and plans is that they are only great on paper if they are not implemented. Why has this strategy not been implemented? Is the problem with funding, the will to implement it, or is the infrastructure not there to do it?

Ms Magdalen Rogers: I thank Deputy Canney for attending the launch of our Patients Deserve Better campaign on Tuesday. We are highlighting the shortage of neurology nurses. Sometimes there is confusion about what is neurology and what is neurorehabilitation. They are two sides of the same coin in that there is a lack of services at all stages of the continuum, as Dr. Pender said. We find that neurology is under pressure because there are no neurorehabilitation services. The same problems and issues that arise with long-term disability are coming back to knock on the door of neurology because the services do not exist in the community. For patients such as the one from which the committee heard on Tuesday, it does not matter whether the gaps are in neurology or neurorehabilitation. At the end of the day, these patients do not have the services they need.

In response to the Deputy's question on why the strategy has not been implemented, from our side in the neurological alliance, sitting on that steering group and not having it meet is a reason. As I said, it has met only twice since the framework was launched in 2019; it did not meet at all in 2021. For us, that has to be seen as a lack of will and a lack of commitment. I understand there have been issues with staffing changes in the HSE and that has been outlined to

us. We have been told by the HSE that there is a commitment to the strategy group meeting in 2022. It is critical that meeting happens because there has been effectively no progress on this implementation plan, and we cannot put that down to Covid. It was happening before Covid. We have had a decade to implement the strategy. It is not just the three-year implementation plan; the strategy was published ten years ago this year and we have seen a lack of implementation and a lack of support for it. To answer the Deputy's question, it has to be seen as a lack of commitment and a lack of will at this stage.

Deputy Seán Canney: I have one question in relation to the idea of the family caring. There seems to be a mishmash of services and breakdowns of services and no joined up thinking. For example, when a young couple is told their child has autism or is diagnosed with something, they find it very hard to access the services. They do not understand where they need to go. There does not seem to be a communication network where one step leads to another step and there is a clear pathway. They go to see somebody and get an assessment and think that is it. Then they realise they have to go some place else but are not told that. They have to do all of this with the trauma of coming to terms with everything that might be happening to their child. What should be implemented so that the services, especially for children, are co-ordinated in a way that can be brought into adulthood for people who have special needs? I presume this is the whole area of co-ordination and leadership. Even accessing the information seems to be a problem. I am just throwing that out as well.

Chairman: Who wishes to come in there? I call Mr. Hennessy.

Mr. Michael Hennessy: I have a couple of things to say in respect of the questions Deputy Canney raised on a family with a diagnosis of, for instance, autism. First, we mentioned that the progressing disability services need to be fully completed, because they are still a work in progress in many parts of the country. That is an issue because a person must go from unit disciplinary teams where they might have gone to one service for autism, another service for physical disability and another service for intellectual disability. Having a single point of contact is important. That is in place in parts of the country. It is not in place in others, but it is getting there. The urgent completion of that is very important. Identifying teams with significant caseloads where the resourcing needs to come up to the levels as they are around country is hugely important.

In terms of the pathways, co-ordination between education and disability service, particularly on pathways through life, is an area that could be improved, for example, through education into employment and into services. We have advocated for guidance counsellors in special schools so that people are made aware of the range of options that are available to them, which enables families and people to make the best possible choices.

Deputy Seán Canney: Are local authorities the best places to have housing adaptation grants administered? What are the experiences with the administration speed of the grants and the level of the grants?

Dr. Alison Harnett: The focus of our work tends to be in the support area and some of the responsibilities cross between Departments, which is often where the citizen finds it difficult. It can be difficult sometimes to identify whether it is the support need or the housing need that drives the adaptation. This can lead to a situation where responsibility is not clear and that leads to a lack of meeting that adaptation cost. Much of the advocacy work that has gone into the new strategy - which obviously has not been published yet - has been taking place to support a very clear delineation of where the budget lines should be for the different types of adapta-

tion and what the ceilings should be. Ultimately, if a person's adaptation need is a little higher than what is at the ceiling, but it means that person can remain in the home and not access a residential place then, obviously, it is good value for the State. What we need to see in the new housing strategy is the State acting in one strategy. For example, if we in the support side and somebody on the housing side are taking different approaches, the person can fall between two stools. Departmental responsibility is crucial. I think Ms Jackson also has some points on this.

Ms Natalya Jackson: To answer the Deputy's question on going through various councils, in some county councils it works very well and in other areas of the country there is evidence it does not. For example, if a resident with an intellectual disability is seeking a rent supplement and it goes through the Department of Social Protection, the buildings are defined as institutional dwellings even though they are living in community houses. That is having an impact on accessing grant supplement which, again, is in breach of their rights and we get back to the UNCRPD.

Dr. Harnett's point about accessibility goes back to the whole area of decongregation. There are a lot of residents with intellectual disabilities who could and should live in the community, but to avail of community houses there are significant adaptations needed. Sometimes the funding, through the various county councils, from the capital assistance scheme, CAS, does not meet the considerable financial requirements that go into those housing models. Again, this should form part of the housing strategy. The needs of people with intellectual disabilities should be identified at the beginning of housing developments; it is a question of getting in early with them.

Chairman: I call Senator Murphy, who is substituting for Senator McGreehan.

Senator Eugene Murphy: Senator McGreehan was very anxious that I would attend this morning and speak, if possible. Unfortunately, she cannot be here. First of all, I wish to express my thanks to all of our guests this morning. It is interesting to hear their comments and presentations. I am well aware, from people and groups I know, of the great work that Dr. Pender is doing.

I strongly support the comments of my colleague from the west, Deputy Seán Canney, in relation to the neurology department at University Hospital Galway, UHG. I was told there are four specialist nurses there and they probably need about 12 or 13. I was reading some documentation only last week about this from the Neurological Alliance of Ireland. It made a very good point that if we had the extra nurses there, it could be a cost efficient way of reducing waiting lists and dealing with hospital resources. Obviously, a consultation process may show that some of the people suffering with neurological issues do not need to be hospitalised. Therefore, if there were extra nurses to make contact with and to advise people in a certain way, it would be very helpful.

Dr. Pender might be the person best able to answer my next question, but I would welcome a comment from any of the witnesses. I know a number of people who are suffering from neurological conditions, particularly back pain, and they cannot get identified as a person with a disability. I am speaking not about people who have back pain for six weeks, but people who have intermittent back pain over many years. I know people who, owing to accidents, have artificial hips or knees. While for the rest of their lives they can live near normally, many of them suffer extraordinary pain. When it comes to a person being identified as a person with a disability, is there anything we can do to change the goalposts in that regard? I am sure all of our witnesses would agree that there are a number of people in Irish society who suffer continuous pain, much

of it back pain, but they cannot access any of our disability services.

On the issue of ensuring that all people with disabilities can access public health services, as a public representative I meet many people who have a family member with a disability for whom they cannot access disability services. Some of them are entitled to those services. In fairness to the HSE and others, when one brings forward a case it is looked after. Why are some people falling through the cracks when they should be eligible as of right? I am sure my political colleagues have come across this issue as well. I would welcome comments from all of the witnesses on how we can ensure that people with disabilities across all groups can access public health services without having to seek the assistance of a politician? We do not mind helping people, but access should be there of right. People should not have to go looking for it. I again thank the witnesses for their presentations. I look forward to hearing their responses.

Dr. Niall Pender: I thank the Senator for raising those issues. He is correct on both counts. Chronic and long-term pain or neurodisability is extremely common and it can be treated with a multidisciplinary pain management programme, but not everybody has access to those programmes and not everybody can get access to them in the region in which they live, as highlighted by the Senator in regard to Galway. The same issues arise across the country in local areas and local hospitals, where people have to fight extremely hard to get access to the services they need. Pain management and long-term, chronic pain in the context of neurodisability is horrendous. It is incredibly disabling. It disrupts people's lives and it means they cannot work. They struggle. As stated by the Senator, sometimes the pain is intermittent. Most of it is back pain, but it can involve headache and any other limb and joint pain arising from the injury and disability. I fully agree that these people need access quickly. That is part of the joined up thinking piece we want to bring together in the new rehabilitation strategy, no matter what the issue. There are a range of complexities. It could be cognitive, pain or motor but usually we end up seeing a constellation of pain, physical disability, cognitive impairment and psychological distress or mental health problems. Those four issues are the pillars that people experience after a neurological injury or with a neurological disability. They need someone to guide them into the services and access to them.

The access piece for neurodisability is really challenging because these people do not know where to go or what services exist. To be honest, most people are thrown into these neurological disabilities without any knowledge. I have relatives and friends who have a family member with a disability asking me where they can get help for their relative. I cannot tell them, because I do not know; the information does not exist. It is heartbreaking to see people almost begging for help, desperate to get access to the help and resources they need, which is sometimes dependent on where they live or what their difficulties are. We need a process where people do not have to fight for access to services. When you have a family member with a neurological disability or any of the other disabilities we are hearing about today, the person dealing with it, the carer, may not have the energy to fight for the services. Many of these people suffer their own mental health problems. We know that the subjective and objective burden from care-giving is enormous, particularly in neurodisability. The subjective burden of dealing with somebody who has perhaps light chronic pain or a psychological difficulty is enormous. It cannot be seen, but it is hugely demanding. The caregivers also do not have time or the energy to go looking for services and to fight for them. Nevertheless, the first thing I hear from many of the people I see at my clinic is that they are exhausted trying to fight for services and that they have gone to everybody possible for help. Nobody should have to fight for services and their right to get treatment for their neurological condition or their disability when we know those treatments exist and that they are very effective.

I support 100% the Senator's remarks. For us in neurological disability, implementation of that document will help us start the ball rolling. We are still light years behind what I am hearing discussed today in terms of housing and the other issues. We are far behind that even now. The trauma plan has been instigated such that we will have excellent state-of-the-art trauma services for people following injury. More people are surviving and so more people will be left with long-term disability and difficulties from these injuries. We need to have somewhere for them to go and we need to have a clearly mapped out plan such that they do not have to fight and battle for services. We do not need to add to their disability. At this moment in time, the system around the infrastructure is increasing and adding to their disability when it does not need to. That makes the pain worse. It makes the emotional pain and the mental health worse as well. I wish I had a clearer answer. We have a pathway already laid out in the neurorehabilitation strategy, which will get us on the ladder and get scaffolding around people, but we still have a long way to go in terms of having the state-of-the-art services.

Chairman: I thank Dr. Pender. Would any of the other witnesses like to comment?

Dr. Alison Harnett: I will make a brief comment on the Senator's question with regard to access to public health. As we witness the transition of disability policy to the Department of Children, Equality, Disability, Integration and Youth, there is an important safeguarding needed for the health services. While disability services are under the aegis of the Department of Health, there is a close connectivity between the health services accessed through disability. There is a real need for everybody to be cognisant of safeguarding that access and that connection as disability moves into a different Department. I am sure everybody is very aware of that, but we need to ensure those connections are maintained and strengthened so that people can access the health requirements they have even though the disability side has been moved to another Department.

Chairman: I thank Dr. Harnett. Would Mr. Hennessy like to comment?

Mr. Michael Hennessy: I thank the Chairman. With regard to the question on people with a disability not accessing services they should be accessing, we would advocate that the UN-CRPD and the rights enshrined within it need to be seen as a whole-of-government response. There has been a tendency in the past to look at a person with a disability at all times through the prism of that disability. We need to accept that while a person may have a disability, that is just one aspect of his or her life. That person is a citizen, a member of a community, a son, a brother, a neighbour, a friend. We need to take the view that persons with disabilities should not access everything through disability services. We need to see access through all parts of the public services be that health, mental health, transport, housing, elder care and so on. All of those must be brought into line with the UNCRPD and all must be disability-proofed so that a person with a disability can access them directly without having to go through disability services or, indeed, a public representative. It should be easier by looking at it that way.

Chairman: I thank the witnesses from the Neurological Alliance of Ireland and the National Federation of Voluntary Service Providers. Having listened to the evidence this morning, the two phrases, "unmet need" and "multiannual funding" stand out for me in regard to the challenges on the neurological side. There is an issue in regard to the strategy and the group not having met yet, which we will take up and follow through on because that is totally and absolutely unacceptable. Some witnesses and members spoke of the challenges all families face in accessing diagnoses and therapies and the change in the reconfiguration of services that has caused a major upheaval. I am glad that upheaval was acknowledged. Major challenges face the services. I have some questions for the representatives of the National Federation of

the Voluntary Service Providers. On foot of all the evidence given, we must follow up on the non-meeting of the strategy group and on the unmet need for disability services.

Do the voluntary service providers and voluntary organisations have a staffing challenge as against the services provided by the HSE? Do they also have an issue in providing staff increments with respect to increments dating back to, say, 2008 or 2009?

Insurance is another issue. Some of the service providers with which I have been dealing have raised the issue of getting independent insurance. A great deal of their fund-raising goes towards paying their insurance costs alone, not towards covering the cost of the services required for people with disabilities. The voluntary organisations have provided a massive service during the past 50 years since they started off in the late 1960s and they have stepped in where the State abandoned the provision of such services. There is now an attempt by the HSE to abandon the voluntary organisations and to streamline the services into the HSE. That would result in the loss of the community based agenda of those services and the ethos underpinning them which is to try to help everybody and to provide for them in their own communities. I have a number of issues with respect to all of that. We will discuss the unmet needs for disability services. We will also discuss the strategy group not having met, which is unacceptable. Meetings can be arranged electronically at present. There is no issue about that. We will follow up on that. Will the representatives of the voluntary organisations give their views on staffing and recruitment, the attempt by the HSE to almost silence the voluntary organisations and on the insurance issue? Dr. Harnett might respond first.

Dr. Alison Harnett: The Chairman has raised a number of key questions for the voluntary sector. The sustainability of the voluntary sector is something we have called for in our response to the disability action plan 2022-2025. With respect to the relationship based supports, people who have a disability are often people who are supported throughout their lifetime by the voluntary service providers. That continuity and relationship based support is very challenged when there is a large turnover in the volume of staff and there are particular challenges for our entire sector. Currently, there are staffing recruitment and retention challenges throughout various sectors but we are experiencing it very acutely in the disability services. That is challenging our ability to move forward with some of the issues about which we spoke this morning. There are particular challenges for different sectors within our membership.

Given the current challenging recruitment environment, and the Chairman referred to staff increments and pay, recruitment is an even more acute challenge for section 39 organisations. While we very much welcome the pay restoration process that has been in place, the gap between section 38 organisations and HSE funded services and those provided by section 39 organisations continues to grow. The ultimate problem with that, with respect to a person supported by an organisation, is that the level to which an organisation can expect its staff to remain and be sustained should not depend on the funding arrangement in place with the State. We consider there is a need for a workforce planning stream within the disability capacity review action plan that would take account of the entirety of the sector, regardless of which funding arrangement is in place with the State. All our members are very challenged with respect to staff recruitment and retention. There is also a need to specifically examine those issues that are particular to section 39 organisations.

In terms of insurance, access to the clinical indemnity scheme would be the ideal solution for those service providers which cannot access it currently. That would alleviate some of those difficulties to which the Chairman rightly referred.

In terms of the community focus our organisations bring, we have voluntary service provider boards and community connection throughout every village and town in Ireland. We need to be able to maintain those staffing levels to be able to continue to make connections and provide that relationship-based support. We believe there is significant importance attached to the independent review group dialogue forum with respect to teasing out some of the issues, to which the Chairman referred, and ensuring the value of the voluntary sector, as identified by the Catherine Day report, is reflected in the working through of the relationship between the State and the voluntary sector. We are committed to the implementation of the recommendations in the Catherine Day report and are very much engaged in the dialogue forum. We are hopeful of very significant outcomes from that process to deal with those issues about which the Chairman spoke, which are around understanding and valuing what the voluntary sector brings to the State with respect to disability services.

Chairman: I thank Dr. Harnett for her response. Mr. Hennessy might also respond.

Mr. Michael Hennessy: I would like to address the three points the Chairman raised when summing up, namely, staffing, insurance and the sustainability of the voluntary sector, and I will deal with them individually.

In respect of staffing, certainly our member organisations are reporting serious difficulties with staffing. Maintaining services, which are very much human services and people dependent services, is a real issue. Our sense is that it is probably a medium-term issue. I do not think this issue will disappear with the pandemic unemployment payment or the Covid-19 crisis. It is more complex. There is a significant job of work to be done for our sector and member organisations on how we attract and retain staff into the future. We will have to work harder domestically on that and we will probably have to consider overseas recruitment. This will be a medium-term issue, particularly if we can persuade the State to resource the unmet need identified in the capacity review. That will require a significant uplift from a base where we are struggling to maintain what we have. There is a considerable job of work to be done in that regard.

Insurance is an ongoing issue for many people who are providing services. The nature of disability services is that they have a risk profile. Many of the organisations which supply those services are relatively small. Therefore, their negotiating power in getting insurance is limited. I will mention two issues in that respect. As well as the clinical indemnity scheme, the general indemnity scheme operated by the State Claims Agency has been extended to some disability service providers. It has proved enormously helpful when it has happened. If that could be widened, it would make an enormous contribution. There is the wider issue of competition for some categories of insurance. If one is lucky, one will have one underwriter. They can dictate terms to organisations. There may be a case to be made for setting up a collective purchasing scheme. Regardless of whether that would be organised on a statutory basis or privately, it would contribute.

In respect of the sustainability of the voluntary bodies, the relationship between the HSE and the voluntary service providers during the past ten years probably has not been as good as it is now. There has been a very heavy focus on governance which is necessary. Public funding is being provided and there must be accountability for it. There has not been enough of an emphasis on partnership working. That improved significantly during the course of the Covid-19 crisis. However, we should not rely on a crisis to fix these things. We cannot assume that just because it has improved during the Covid-19 crisis, it would stay that way. There is a body of work to be done by the HSE and by the voluntary sector to improve that relationship and particularly to get partnership working on solutions. We attach considerable importance to

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the dialogue with the voluntary bodies being chaired by Peter Cassells. That needs to produce outcomes that sustain the recent improvement in that relationship.

Chairman: I thank all the witnesses for attending and for giving of their time and expertise. Their input will feed into the work of the committee. I also thank the members for their dedication and commitment. This is an ongoing discussion and process. We will be in touch with the witnesses. We will shine a spotlight on the issues raised to try to get resolutions to them. That is what we are about. On the issues of unmet need, the multiannual funding and the commitments in regard to the strategy, we will follow up on and continue to engage with the witnesses on them.

I thank our team for their ongoing co-operation and work. I remind members that the joint committee will meet in private session next Monday at 3 p.m. to go through its work schedule. The next public meeting is on Thursday, 9 December 2021.

The joint committee adjourned at 11.40 a.m. until 9 a.m. on Thursday, 9 December 2021.